PROFILE

Chloe Hayes

LIVING WITH JUVENILE HUNTINGTON'S DISEASE

"Huntington's is like having Alzheimer's, Parkinsons' and Motor Neuron Disease at the same time"

Chloe Hayes lives with her mother Geraldine in Mullingar. 18 year-old Chloe has Juvenile Huntington's Disease, a hereditary neurodegenerative condition. Geraldine remembers Chloe as a bright and happy schoolchild. At seven, Chloe started to experience rigidity of movement and uncharacteristic temper tantrums. Her teachers were concerned as her progress at school deteriorated. When her National Educational Psychological Service (NEPS) assessments indicated learning difficulties increasing over time Geraldine pushed for Chloe to have further tests and she was eventually referred to a Pediatrician.

Chloe's parents split up before she was born and she grew up with little contact with her Dad. When Chloe was nine, Geraldine received the devastating news that Chloe's Dad had Huntington's Disease (HD) and was living in a nursing home. HD is hereditary. Each child of an affected parent has a 50% chance of inheritance. Symptoms usually appear between the ages of 35 and 50 years but about 5-10% of people with HD become symptomatic before age 20 (Juvenile HD).

An official diagnosis of Juvenile HD three years later confirmed Geraldine's worst fears. Chloe had to leave her school after first year, so Geraldine decided to relocate from their home in County Meath to Mullingar. There, Chloe could attend St Brigid's Special School and they had family support nearby. While at St Brigid's, Chloe availed of speech and language therapy, physiotherapy and occupational therapy and both she and Geraldine received excellent support from the school. Geraldine said,

'Huntington's is like having Alzheimer's, Parkinsons' and Motor Neuron Disease at the same time. As a mother I am often overwhelmed by the challenges Chloe endures but her magnificent smile keeps me going, her graduation last year was a very proud and happy time for us all'.

RARE DISEASE

About Huntington's Disease (HD)

Huntington's Disease is a life-limiting genetic neurodegenerative illness caused by a mutation in the 'Huntington' or 'HD' gene which leads to the destruction of certain brain cells. As brain cells die physical, cognitive and emotional symptoms appear and gradually worsen over time. In Juvenile HD the symptoms occur in childhood or adolescence and tend to follow a more rapid course.

In Ireland there are approximately 700 people living with HD and a further 3000 people at risk. Currently there is no cure however specialist multi-disciplinary treatment and care is essential to manage symptoms and enhance quality of life. Recent advances in research worldwide bring significant hope of gene therapies to target the root cause of HD.